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ABSTRACT

Results are reported of a pilot study to determine the effectiveness of a tracking program to maintain high risk infants in continuing health care, determine health and developmental outcomes, and survey the use of community resources in this population. Subjects were 766 infants from six participating hospitals in two Washington counties, one of which participated in the study for 4 years, the other for 3. Infants were identified within the first 30 days of life according to 17 criteria incorporating medical, social, and environmental risk factors, and 78 percent of infants identified were enrolled in the project. Both counties have maintained greater than 85 percent of the high priority infants identified and enrolled in ongoing health care and developmental surveillance. The largest group had low birthweights, and the majority presented more than one eligible criterion. Medical problems identified at 3, 6, and 12 months were predictive of later medical problems. The local health department was the most frequently reported community resource used. Tentative conclusions indicate that an organized, systematic tracking program can keep high priority infants in ongoing primary health care and assure timely identification and referral for further evaluation of potential health and developmental problems. (JW)

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Washington State
High Priority Infant Tracking Project

Pilot Project Update
October, 1982 to April, 1987

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ABSTRACT

WASHINGTON STATE HIGH PRIORITY INFANT TRACKING PROJECT

In 1982 the Washington State Bureau of Parent Child Health Services in coordination with the Child Development and Mental Retardation Center, University of Washington implemented a pilot study to determine the effectiveness of a tracking program to maintain high risk infants in continuing health care, determine health and developmental outcomes, and survey the use of community resources in this population.

Whatcom County has completed four years of pilot study. Thurston County was added in May, 1984 and has completed three years of participation. Infants enrolled in the PILOT PHASE of the Washington State High Priority Infant Tracking Project are those infants born between October 1, 1982 and April 30, 1986. A total of 766 infants from six participating hospitals have been identified.

Infants were identified during the pilot phase within the first 30 days of life according to 17 criteria incorporating medical, social and environmental risk factors. The project has enrolled 78% of the eligible infants. Data is collected at pre-determined tracking points of 3, 6, 18, 24 and 36 months via postal questionnaire to the primary care provider. Community health nurses follow up on any infant who drops out of care during the tracking period, and reconnects the family with the health care system when possible. Both counties have maintained greater than 85% of the high priority infants identified and enrolled in ongoing healthcare and developmental surveillance.

The largest group of high priority infants had low birthweights $\leq$ 2500 grams (N=282). Other frequent indicators were environmental, social or parenting concerns (N=233), respiratory problems (N=142) and birth defects (N=119). A total of one hundred infants were identified as doubly vulnerable by presenting both medical and environmental/social/parenting risk factors. The majority of infants were identified by presenting more than one eligible criteria (66%).

Medical problems identified at 3, 6, and 12 months were predictive of later medical problems. ($p < .01$). A similar relationship was noted between early tracking periods three, six and twelve months, for predicting the occurrance of developmental concerns at the eighteen month period. A

significant relationship ($p \leq .05$) between early health problems and later developmental problems was identified. The overall incidence of health problems in the sample population was forty percent (40%). Developmental problems were noted in approximately twenty percent (20%).

The most frequently reported community resource used by high priority infants and their families was the local health department. Referral to other specialists/consultants were used by thirty percent of the cases. Most infants were monitored by a primary care provider in their local community.

Tentative conclusions based on four years of data collection indicate that an organized, systematic tracking program can keep high priority infants in ongoing primary health care and assure timely identification and referral for further evaluation of potential health and developmental problems. The Washington State High Priority Infant Tracking Project will begin a four year statewide expansion phase in July 1987. State funds have been encumbered to implement the project in fifteen additional counties.

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SECTION I

INTRODUCTION

INTRODUCTION

In October, 1982 the Washington State Department of Social and Health Service Bureau of Parent-Child Health Services, in coordination with the University of Washington, implemented the High Priority Infant Tracking Project (HPIT) as a pilot project in Whatcom County, Washington. To evaluate the effectiveness of the tracking system, Thurston County, Washington was added to the pilot project as a matched county in May, 1984. The primary objectives of the project are as follows:

1. To help parents keep their child under the care of their primary physician.
2. To promote early identification of infants requiring further evaluation, or services.
3. To assist in planning for the health and educational needs of the children of Washington State.

Infants enter the HPIT project by first identifying high priority infants according to "high priority" indicators listed on the IDENTIFICATION FORM (see Appendix A). Infants may be identified using one or more of the seventeen criteria including medical, social, parenting, or environmental risk factors. The IDENTIFICATION FORM is then completed, noting the risk factors identified, and consent is obtained from the infant's parents and the primary health care provider. A copy of this form is then sent to the public health department, and enrollment into the tracking system is completed.

A TRACKING FORM (see Appendix B) is sent to the infant's primary care provider at three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. This form requests information regarding the infant's health and developmental status, use of community services and the status of ongoing health care. If the health care provider indicates the infant is not receiving care, the community health nurse attempts to locate the family and reconnect them with the health care system. Follow-up activities by the community health nurse may include written communication with the family and the primary care provider, telephone calls and home visits.

The High Priority Infant Tracking Project has now completed a pre-pilot study and four full years of the pilot study. The following data is derived from the analysis of information obtained from six participating hospitals, two public health departments and private health care providers caring for infants residing in Whatcom and Thurston Counties.

During the time period from October 1, 1982 to April 30, 1986 439 infants from Whatcom County and 327 infants from Thurston County have been identified as "High Priority." This report provides a description of the data obtained from these 766 infants as well as tracking information for 598 infants who are participating in the tracking phase of the project.

During the pilot phase of the project 78% of the eligible infants were successfully enrolled in the project.

SECTION II

COUNTY HEALTH DISTRICT FINDINGS

WHATCOM COUNTY

WHATCOM COUNTY

Whatcom County has now completed four and one half years of the pilot phase of the High Priority Infant Tracking Project. During the pilot phase identification period from October, 1982 to April 30, 1986, four hundred and thirty-nine (439) infants who were residents of the county were identified as eligible for the project. Sixty-seven percent (67%) or two hundred ninety-five (295) infants were successfully enrolled in the project and are at different tracking phases, or have been dismissed from the tracking project after completion of the 36 month tracking period.

The one hundred and forty-four infants were not enrolled for the following reasons:

-	Physician Refusal:	89 infants	(20 percent)
-	Parental Refusal:	17 infants	(4.0 percent)
-	No Parent Signature:	12 infants	(2.5 percent)
-	Moving:	8 infants	(2.0 percent)
-	Adopted:	8 infants	(2.0 percent)
-	No Reason/Blank	6 infants	(1.0 percent)
-	Wrong County	2 infants	(.5 percent)
-	Missed:	2 infants	(.5 percent)
-	Baby Expired	1 infants	(.2 percent)
			32.7 percent

Identifying Hospitals

The infants included in the Whatcom County High Priority Infant Tracking Project were primarily identified at three hospitals known to care for infants from Whatcom County, Washington. These hospitals include Children's Hospital and Medical Center, Seattle, Washington; University Hospital, Seattle, Washington; and St. Joseph's Hospital, Bellingham, Washington. Additionally, infants missed during their hospitalization who were eligible for the project, or who born outside of the hospital can be later identified either by the Public Health Department or the infant's private health care provider. Infants can be identified at any time during the first thirty days of life through physician's request, home visit by a community health nurse or well

child visit. The number of infants identified by each individual source is as follows:

Children's Hospital and Medical Center	25 cases	(6 percent)
University Hospital:	15 cases	(3 percent)
St. Joseph's Hospital:	350 cases	(89 percent)
Public Health Nurse/ Physician	7 cases	(2 percent)
Total	439 cases	100 percent

Number of Infants Identified Per Pilot Project Year:

The pilot project for Whatcom County began in October, 1982. As can be seen below, the number of infants identified as 'High Priority' and who have 'Identification Forms' completed has generally increased with each project year:

- October 1, 1982 to December 31, 1982 — 11 infants (3.6 per month)
- January 1, 1983 to December 31, 1983 — 60 infants (5.0 per month)
- January 1, 1984 to December 31, 1984 — 155 infants (12.9 per month)
- January 1, 1985 to December 31, 1985 — 164 infants (13.6 per month)
- January 1, 1986 to April 30, 1986 — 49 infants (12.25 per month)

Comparison to Whatcom County Births

In 1985 Whatcom County reported an annual live birthrate of 1,618. HPIT Project eligibility estimates indicate that ten to twelve percent of all live newborns could potentially be identified as eligible for the project. Estimates at ten and twelve percent are shown below.

1985 birthrate	10%	12%
1,618	162	194

In the project year 1985, Whatcom County identified 164 infants or ten percent of all newborns.

Tracking Process

Once an infant is identified as high priority, both physician and parental agreement to enroll the infant into the tracking program is obtained. The infant is then placed on the tracking schedule of 3 months, 6 months, 12 months, 18 months, and 36 months. All 295 infants with completed 'Identification Forms' and appropriate consents obtained have been placed on this schedule by the Whatcom County Public Health Department, and are presently at different stages of the tracking program.

The numbers of completed forms for each tracking period is depicted in TABLE 1.

TABLE 1
HPIT Project: Whatcom County
Completed Tracking Forms

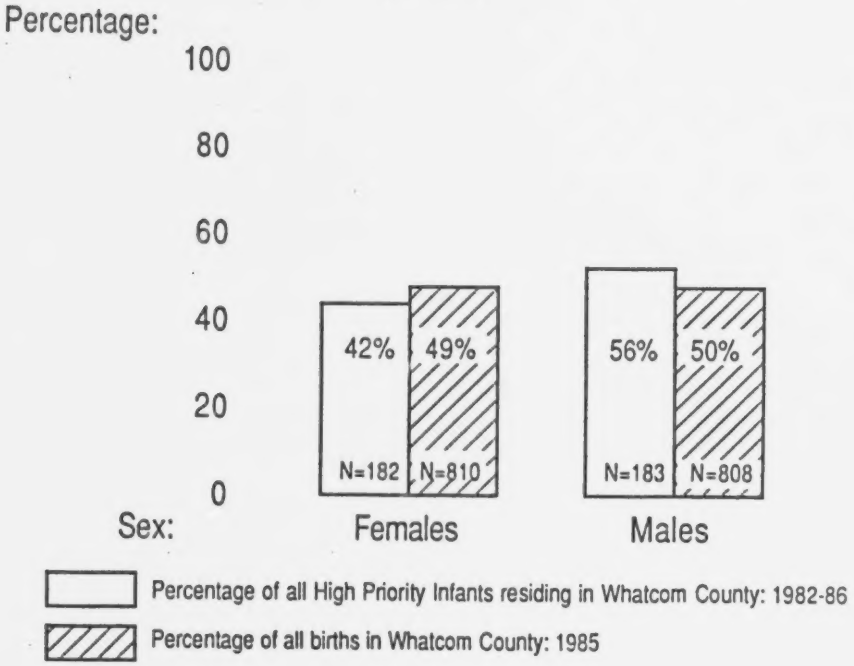
Tracking Period	Number of Forms Completed
3 months	265
6 months	257
12 months	214
18 months	173
24 months	133
36 months	47

Characteristics of Whatcom County High Priority Infants

Sex:

Fifty-six percent (249 infants) of the high priority infants were male, 42% (182 infants) were female. The sex of the infant was not reported in eight cases. This preponderance of males to females compared with the reported county distribution is shown in Figure 1.

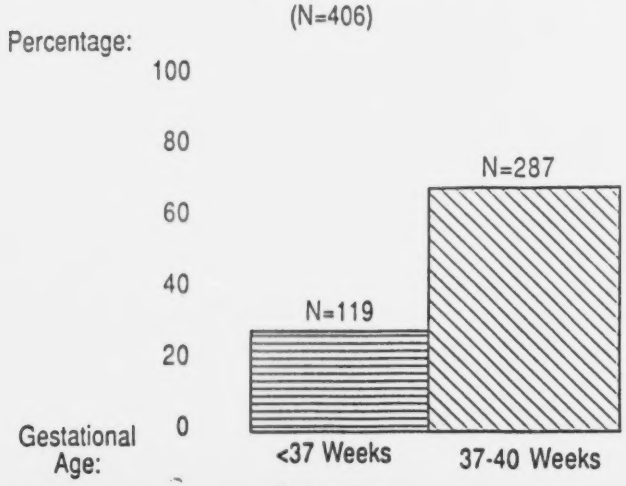
Figure 1:
Sex of High Priority Infants
Compared with Whatcom County Births: 1985
(N=431)



Gestational Age:

Information regarding gestational age was available for 406 infants. Of these infants, twenty-nine percent (119 infants) had reported gestational ages of 36 weeks or less. Seventy-one percent were born at 37 weeks or greater (287 infants). The range of gestational ages reported was 24 to 43 weeks, with a modal age of 40 weeks. Information regarding gestational age was not reported in 33 cases. See Figure 2.

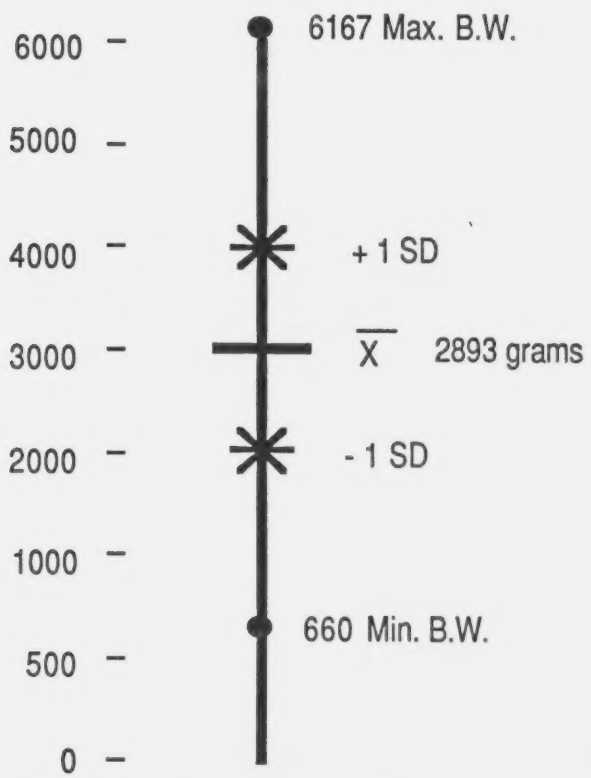
Figure 2:
Gestational Age of High Priority Infants
Residing in Whatcom County
(N=406)



Birthweight:

The mean, or average birthweight for these infants was 2893 grams (S.D.=823 grams), with a range of 660 grams to 6167 grams. An illustration of the average birthweight for Whatcom County High Priority Infants is found in Figure 3.

Figure 3:
Average Weight of Whatcom County
High Priority Infants



Average weight = 2893 grams; SD = 823 grams
Minimum weight = 660 grams; Maximum weight = 6167 grams

Identicators of High Priority:

Each infant identified as "high priority" in Whatcom County had up to five different criteria checked on the 'Identification Form.' Table 2 indicates the number of times an indicator was checked for the 439 identified high

priority infants up to April 30, 1986. FIGURE 4 further illustrates the distribution of high priority indicators.

TABLE 2

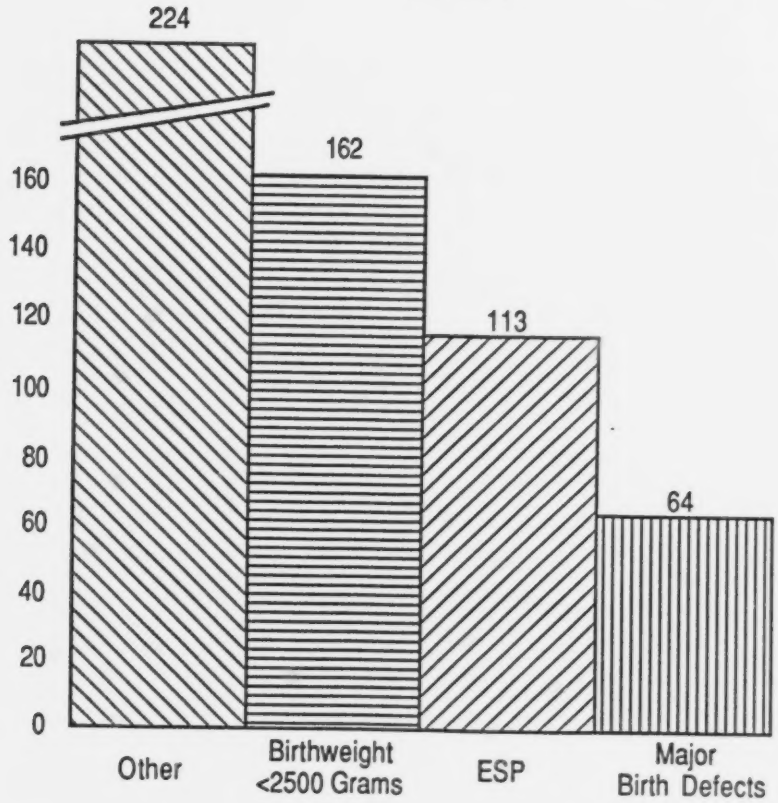
WHATCOM COUNTY

INDICATORS OF HIGH PRIORITY

Birthweight less than 2500 grams:	162
Small for gestational age:	45
Occipital-Frontal Circumference less than ten percent:	8
Low APGAR (less than four at five minutes):	7
Intracranial Hemmorhage:	9
Seizures:	13
Neurological Disorders:	12
Central Nervous System Infection:	2
High Bilirubin (Greater than 20):	29
Hearing impairment:	2
Visual impairment:	2
Major Birth Defect*	64
Chromosome:	3
Musculoskeletal:	9
Cleft lip/palate:	6
Major gastrointestinal:	11
Cardiac Anomalies:	25
Central Nervous System:	2
Other:	8
Congenital Infection:	14
Hypothyroid:	0
PKU:	0
Mother less than 15 years of age:	17
Enviromental/Social/Parenting Concerns	113
Other	224

*Note: One infant may have more than one "major birth defect" and/or "other" problem. The most frequently reported problems were noted to be: little or no prenatal care, maternal history of communicable disease, significant respiratory distress, or other minor medical problems.

Figure 4:
HPIT Project: Whatcom County
Most Frequently Reported High Priority Indicators
(N=329)



Health and Developmental Concerns of High Priority Infants:

For each tracking period in the tracking phase of the pilot project health and developmental status, as well as the continuity of care will be examined. Whatcom County has completed data for subjects from three months through thirty-six months. Refer to Table 1 for information regarding the number of project enrollees at each tracking point. Data collected at one time point is independent of other time points.

Three Months

Receiving Care: Two hundred and sixty-five infants had three month forms on file at the time of data analysis. The numbers of infants reported to be in ongoing care, in active follow up by the public health district, or lost to care were reported as follows:

	N	%
In Documented Care	232	87.5
In Active Follow-up	25	9.5
Lost to Care (Case Closure)	8	3
	265	10

The reasons reported for case closure were moved (4), can't locate (1), deceased (1) and other (2).

Health Status

Health Status information was available for two hundred forty-nine (249) infants. Of these, health status was reported as "normal" for one hundred and sixty-one infants (64%). Eighty-eight infants (35%) had one or more significant health concern noted at three months.

The significant health concerns reported at this tracking period are represented in TABLE 3.

TABLE 3
HPIT: 3 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N = 88)

Concern	Frequency
Central Nervous System:	18
Pulmonary:	12
Cardiac:	21
Renal:	6
Gastrointestinal:	25
Growth Disorders:	13
Malformation or Syndrome:	14
Socio-Medical	21
Other:	19

Developmental Status:

Developmental status was reported for 221 cases. Questionable or abnormal developmental status was reported for 27 infants, 12% of the cases. Eighty-eight percent, or 194 infants, had reportedly "normal" development.

Six Months

Receiving care: A total of two hundred fifty-six (256) six months tracking forms were available for review. Infants reported as in ongoing care, lost to follow-up and engaged in active follow-up were as follows:

	N	%
In Documented Care	12	92%
In Active Follow-up	12	5%
Lost to Care (Case Closure)	8	3%
	257	100%

For those seven infants lost to care the reason was reported as moved (5), parent withdrew (1) and deceased (2).

Health Status

Information regarding health status was available for two hundred and forty-seven infants. One hundred sixty-five infants tracked through the six month period have reported "normal" health (67 percent). Eighty-two infants (33 percent) tracked to this period have one or more significant health concerns. The reported concerns are depicted in TABLE 4.

TABLE 4
HPIT: 6 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N = 82)

Concern	Frequency
Central Nervous System:	25
Pulmonary:	16
Cardiac:	18
Renal:	8
Gastrointestinal:	16
Growth Disorders:	9
Malformation or Syndrome:	13
Socio-Medical:	22
Other:	21

Developmental Status

Ratings of developmental status were available for 223 cases at the six months tracking period for Whatcom County. Of these cases, 191 infants or 86 percent had reportedly "normal" development. Abnormal or questionable development was reported in 32 infants, or in 14 percent of the cases.

Twelve Months

Receiving care: Two hundred and fourteen month twelve tracking forms were available for review. Of these cases the following numbers of infants were reportedly under care, lost to follow-up or in active follow-up.

	N	%
In Documented Care	189	88%
In Active Follow-up	17	8%
Lost to Care (Case Closure)	8	4%
	214	100%

For the eight infants who were lost to care at the twelve month tracking point, the majority (7 infants) were lost due to moving, one infant could not be located after extensive follow-up.

Health Status

Health status information was reported for two hundred and four infants. One hundred and twenty-nine infants were reported as having normal health (63%). Seventy-five infants had one or more health concerns noted at the twelve month tracking period (37%). The significant health concerns are reported in Table 5.

TABLE 5
HPIT: 12 MONTH TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N = 75)

Concern	Frequency
Central Nervous System:	16
Pulmonary:	16
Cardiac:	15
Renal:	4
Gastrointestinal:	9
Growth Disorders:	12
Malformation or Syndrome:	7
Socio-Medical:	20
Other:	25

Developmental Status

Physician ratings of developmental status was available for 189 infants. Normal development was reported for 154 infants, or 81 percent of the cases. Thirty-five infants (19%) were reported as having abnormal/questionable development at this tracking period.

Eighteen Months

Receiving care: Whatcom County has contributed a total of one hundred seventy-three (173) tracking forms for review at the eighteen month tracking period.

	N	%
Indocumented Care	124	72%
In Active Follow-up	33	19%
Lost to Care (Case Closure)	16	9%
	173	100%

For the sixteen infants who were lost to care, eleven moved out of state or county, on infant could not be located, four had other reasons for closure.

Health Status

Information regarding Whatcom County infants who had completed the eighteen month tracking point was available for one hundred sixty infants. Of these, ninety-eight infants were reported as having normal health (61%). Significant health concerns wre noted for sixty-two infants (39%). The concerns reported are recorded in Table 6.

TABLE 6
HPIT: 18 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
WHATCOM COUNTY (N = 62)

Concern	Frequency
Central Nervous System:	11
Pulmonary:	12
Cardiac:	16
Renal:	3
Gastrointestinal:	7
Growth Disorders:	8
Malformation or Syndrome:	11
Socio-Medical:	10
Other:	21

Developmental status

One hundred fifty-one cases reported developmental status at the eighteen months tracking period. A total of 126 infants, or 83 percent were reported as having normal development. Seventeen percent, or twenty-five cases were reported as having questionable/abnormal development at this tracking period.

Twenty-four Months

Receiving care. One hundred and thirty-three cases were available for review at the twenty-four month tracking period. At this tracking point, the numbers of infants in care or follow-up were as follows:

	N	%
Indocumented Care	112	84%
In Active Follow-up	12	9%
Lost to Care (Case Closure)	9	7%
	133	100%

The eight infants lost to care reportedly moved (2), parental withdrawal (1), can't locate (5) and deceased (1).

Health Status

Health status was available for one hundred eighteen infants at the twenty-four month tracking period. Seventy-nine infants (67%) had normal health reported. Health concerns were noted for thirty-nine infants (33%). The significant health concerns are reported in TABLE 7.

TABLE 7

HPIT: 24 MONTHS TRACKING FORMS

SIGNIFICANT HEALTH CONCERNS

WHATCOM COUNTY (N = 118)

Concern	Frequency
Central Nervous System:	6
Pulmonary:	4
Cardiac:	2
Renal:	1
Gastrointestinal:	2
Growth Disorders:	4
Malformation or Syndrome:	7
Socio-Medical:	3
Other:	8

Developmental Status

Developmental information was available for one hundred nine cases. Eighty-one percent or 88 infants had reportedly "normal" development. Abnormal/Questionable development was reported for 21 infants or nineteen percent.

36 Months

Receiving care: Forty-seven Whatcom County infants have completed the tracking phase of the High Priority Infant Tracking Project and have completed tracking forms available for review. The number of infants in care, follow-up or lost to care are reported as:

	N	%
In Documented Care	38	81%
In Active Follow-up	7	15%
Lost to Care (Case Closure)	2	4%
	47	100%

Infants were lost to care due to inability to locate (1) or death (1).

Health Status

Information regarding health status was available for forty-one infants at this tracking period. Twenty-three infants (56%) reportedly had "normal" health. Eighteen infants (44%) had one or more significant health concerns noted. These concerns are reported in TABLE 8.

TABLE 8

HPIT: 36 MONTHS TRACKING FORM

SIGNIFICANT HEALTH CONCERNS

WHATCOM COUNTY (N = 18)

Concern	Frequency
Central Nervous System:	4
Pulmonary:	2
Cardiac:	2
Renal:	1
Gastrointestinal:	3
Growth Disorders:	0
Malformation or Syndrome:	3
Socio-Medical:	1
Other:	4

Developmental Status

Developmental status information was available for thirty-nine infants who have completed thirty-six month tracking forms. Physician reporting indicated that twenty-seven infants, or sixty-nine percent had normal development. Twelve infants, or thirty-one percent had developmental concerns reported.

A comparison of the health and developmental status for all six tracking periods in Whatcom County is illustrated in TABLE 9.

Table 9
HPIT Project
Comparison of Health and Developmental Status
in Whatcom County

Tracking period	Health		Development	
	Normal	Abnormal*	Normal	Questionable/ Abnormal
3 Months	64%	36%	88%	12%
6 Months	67%	33%	86%	14%
12 Months	63%	37%	81%	19%
18 Months	61%	39%	83%	17%
24 Months	67%	33%	81%	19%
36 Months	56%	44%	69%	31%

* Abnormal health is indicated by the reporting of one or more significant health concerns

WHATCOM COUNTY: PILOT PROJECT CONTINUITY OF CARE

The pilot phase of the Whatcom County HPIT Project has been successful in maintaining greater than eight-four percent of the identified infants in ongoing, documented well child care.

The percentage of pilot project enrollees that required active follow up at any one tracking period ranged from eight to fifteen percent. For these infants, followup activities conducted by the local health department coordinator might include telephone calls, written followup to parents and primary care providers, as well as home visits. The average percentage of infants in followup was eleven percent. Table 10 illustrates the continuity of care in Whatcom County during the pilot phase of the HPIT Project.

TABLE 10
HPIT: WHATCOM COUNTY
CONTINUITY OF CARE
1982-1986

Tracking Period	% In care	% In Active Followup	% Lost to Care
3 months	87.5	9.5	3
6 months	92	5	3
12 months	88	8	4
18 months	72	19	9
24 months	84	9	7
36 months	81	15	4
Averages:	84%	11%	5%

Reported Use of Community Services

Each tracking form sent to the primary care providers of high priority infants requests information regarding the types of community services utilized by the infants or their families. This question was asked as a way to evaluate the number and type of services used, and as a way to plan for services in the future for these infants. All high priority infants enrolled into the tracking system are followed by the Whatcom County Health Department.

Information regarding the use of services by high priority infants and their families was available for less than thirty percent of all pilot project enrollees in Whatcom County. Due to the extremely limited number of enrollees for whom community service information was available, no generalization can be made from this data.

Table 11 reports the most frequently reported services and the percentage of infants using those services at each tracking point.

TABLE 11

HPIT: WHATCOM COUNTY

MOST FREQUENTLY REPORTED COMMUNITY SERVICES

(Number of Cases)

Tracking Periods	Service Categories				
	N Reporting*	Referral/ Consultation	WIC	Public Health Dept.	CPS
3 months	71	22	10	28	5
6 months	81	36	13	28	3
12 months	53	30	9	16	2
18 months	45	24	6	11	2
24 months	28	20	1	8	1
36 months	12	7	0	0	1

Key: WIC - Women, Infants and Children, Supplemental Food Programs
CPS - Child Protective Services

* Valid cases reporting use of one or more Community Services.

**Some valid cases may use as many as five community services concurrently.

SECTION II

COUNTY HEALTH DISTRICT FINDINGS

THURSTON COUNTY

THURSTON COUNTY

Thurston County has now participated for three years in the High Priority Infant Tracking Project. Three hundred and twenty-seven infants residing in Thurston County have been identified as "high priority." Of these 327 infants 303 infants (93 percent) have been successfully enrolled into the tracking system. The remaining infants were not enrolled due to the following reasons:

-	Physician Refusal	7 infants	(2 percent)
-	Parental Refusal:	3 infants	(1 percent)
-	Adopted:	1 infants	(.5 percent)
-	No Parent Signature:	10 infants	(3 precent)
-	Blank/No Reason Given	3 infants	(.5 percent)
			(7 percent)

Identifying Hospitals

The infants in the Thurston County High Priority Infant Tracking Pilot Project are primarily identified at five hospitals known to care for Thurston County infants. These hospitals include Children's Hospital and Medical Center, Seattle, Washington; University Hospital, Seattle, Washington; Tacoma General Hospital, Tacoma, Washington; Madigan Army Medical Center, Tacoma, Washington; and St. Peter Hospital, Olympia, Washington. Additionally, infants missed during their hospitalization who are eligible for the project, or who are born outside of the hospital can be later identified either by the Public Health Department or the infant's private health care provider. Infants can be identified at any time during the first thirty days of life through a physician's request, home visit by a community health nurse, or a well child visit. The number of infants identified by each individual source is as follows:

Children's Hospital and Medical Center	7 infants	(2 percent)
University Hospital:	0 infants	(0 percent)
Tacoma General Hospital:	12 infants	(4 percent)
Madigan Army Medical Center:	22 infants	(7 percent)
St. Peter's Hospital:	240 infants	(73 percent)
Public Health Nurse/Physician:	46 infants	(14 percent)
Total	227 infants	100 percent

Number of Infants Identified Per Pilot Project Year

The pilot project for Thurston County began May 1, 1984. The number of infants identified during each project year is shown below.

- May 1, 1984 to December 31, 1984 — 75 infants (9.4 infants per month)
- January 1, 1985 to December 31, 1985 — 199 infants (14.5 infants per month)
- January 1, 1986 to April 30, 1986 — 53 infants (13.25 infants per month)

The pilot phase for the Thurston County HPIT project began May 1, 1984, and continued through April 30, 1986. Infants identified during this period constitute "pilot phase enrollees." Information regarding infants identified after May 1, 1986 is reported separately, as those infants are considered "project enrollees" for data management purposes.

Comparison to Thurston County Births

In 1985 Thurston County reported an annual live birthrate of 2203. HPIT Project eligiblity estimates indicate that ten to twelve percent of all newborns could potentially be identified for the project. Estimates at 10 and 12 percent are shown below:

1985 Birthdate	10%	12%
2203	220	264

The Thurston County HPIT Project successfully identified almost the estimated ten percent project rate, with 199 infants identified in 1985.

Tracking Process

Once an infant is identified as high priority, and both physician and parental agreement to enroll the infant into the tracking program is obtained, the infant is placed on the tracking schedule of three months, six months, twelve months, eighteen months, twenty-four months, and thirty-six months. All 303 infants with completed 'Identification Forms' and appropriate consents obtained have been placed on this schedule by the Thurston County Public

Health Department, and are presently at different stages of the tracking program.

The numbers of completed forms for each Tracking Period is depicted in TABLE 12.

TABLE 12
HPIT PROJECT: THURSTON COUNTY
COMPLETED TRACKING FORMS

Tracking Period	Number of Forms Completed
3 months	284
6 months	277
12 months	230
18 months	111
24 months	59
36 months	0

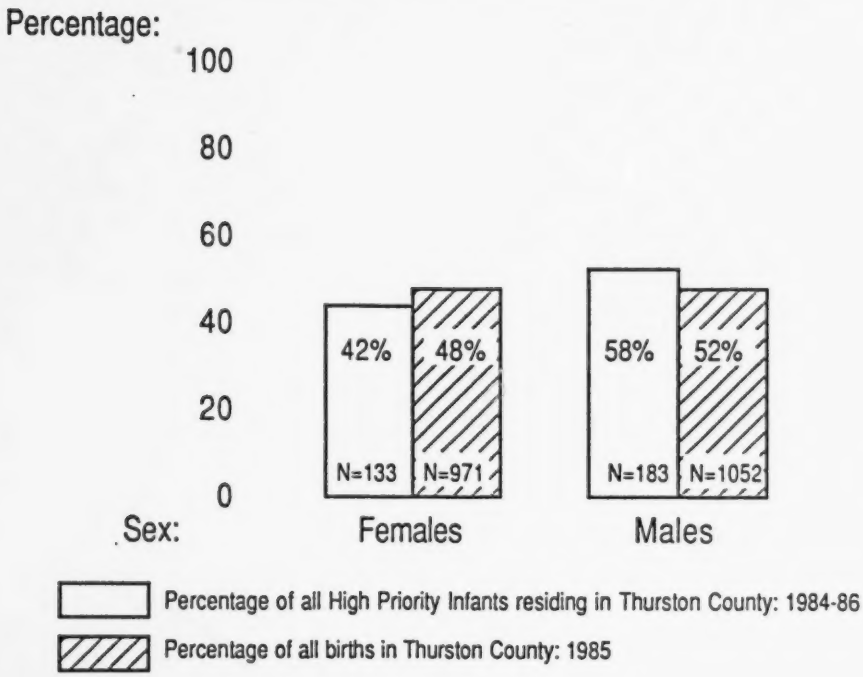
*The first HPIT Project enrollees in Thurston County are currently reaching the 36 month tracking period.

Characteristics of Thurston County High Priority Infants

Sex:

Fifty-eight percent (183 infants) of the "high priority" infants were male. Forty-two percent (133 infants) were female. The sex of the infant was not reported in eleven cases. In Figure 5 the preponderance of males over females in relationship to the county distribution is shown.

Figure 5:
Sex of High Priority Infants From Thurston County
Compared with Thurston County Births: 1985



Gestational Age

Information regarding gestational age was available for 290 infants. Of these infants, thirty-three percent (108 infants) were born before 37 weeks gestational age. Sixty-seven percent (182 infants) were born at gestational ages of 37 weeks or above. The reported range of gestational ages was 25 to 45 weeks. The modal gestational age was 40 weeks. Information regarding gestational age was not reported for 37 cases. See Figure 6.

Birthweight

The mean or average birthweight for Thurston County High Priority Infants was 2845 grams (SD = 894 grams). The range of reported birthweights was from 680 to 5520 grams. See Figure 7.

Indicators of High Priority

Each infant identified could have one or more of the 18 identifying criteria from the Identification Form. Figure 8 represents the number of times an identifying indicator was reported for the 249 infants with completed Identification Forms.

TABLE 13

HPIT PROJECT: THURSTON COUNTY

HIGH PRIORITY INDICATORS

Birthweight less than 2500 grams:	20
Small for gestational age:	23
Occipital-Frontal Circumference less than ten percent:	21
Low APGAR (less than four at five minutes):	3
Intracranial Hemmorhage:	8
Seizures:	10
Neurological Disorders:	10
Central Nervous System Infection:	3
High Bilirubin (Greater than 20):	10
Hearing impairment:	2
Visual impairment:	3
Major Birth Defect*	55
Chromosome:	8
Musculoskeletal:	12
Cleft lip/palate:	5
Major gastrointestinal:	9
Cardiac Anomalies:	18
Major Renal:	6
Minor Birth Defects/Other:	5
Myleomeningocele:	1
Congenital Infection:	4
Hypothyroid:	2
PKU:	0
Mother less than 15 years of age:	18
Environmental/Social concerns	29
Parenting Concerns:	106
Other*:	269

*note: An infant may have more than one major birth defect and/or other problems. The most frequently reported problems were noted to be: little or no prenatal care, maternal history of communicable disease, significant respiratory distress, or other minor medical problems.

Figure 8 indicates the most frequently reported indicators of high priority.

Figure 6:
Gestational Age of Thurston County
High Priority Infants
(N=290)

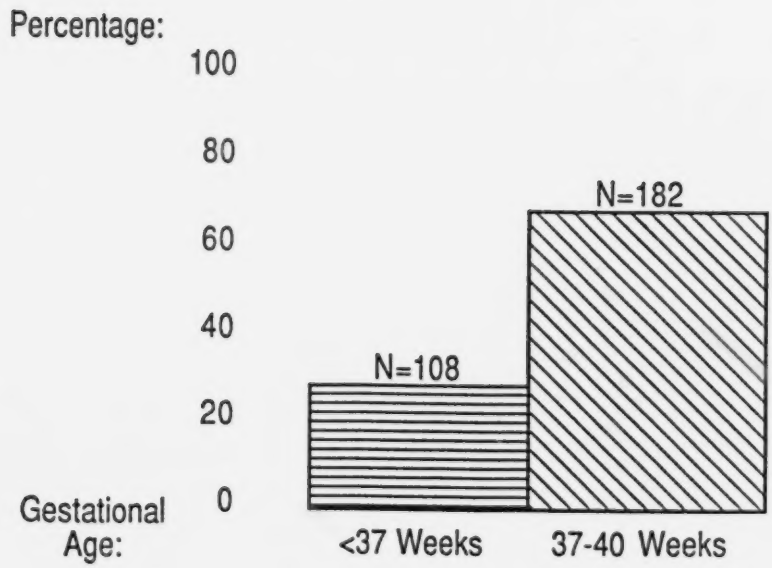
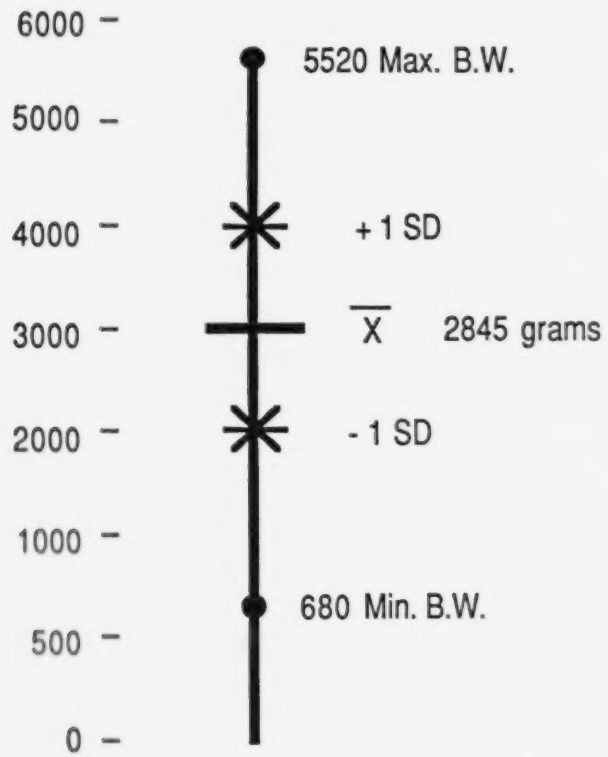
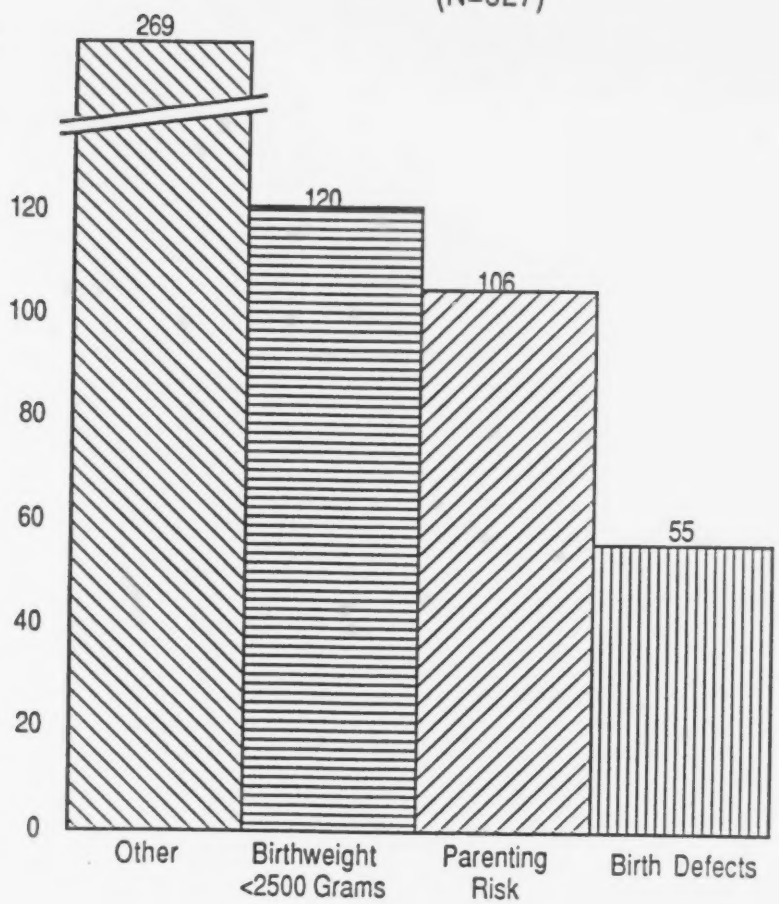


Figure 7:
Average Weight of Thurston County
High Priority Infants



Average Weight = 2845 grams; SD = 894 grams
Minimum weight = 680 grams; Maximum weight = 5520 grams

Figure 8:
HPIT Project: Thurston County
Most Frequently ReportedHigh Priority Indicators
(N=327)



Tracking Phase

Health and Developmental Concerns of High Priority Infants

For each tracking period in the tracking phase of the pilot project, health and developmental status data, as well as the continuity of healthcare was examined. Thurston County has completed data for subjects from three months through twenty-four months. The oldest Thurston County HPIT Project enrollees are just reaching the thirty-six month tracking period. Refer to Table 12 for information regarding the number of project enrollees at each tracking point. Data collected at one time point is not independent of other tracking points.

Three Months

Receiving care. Two hundred and eighty-four three month tracking forms were available for review. The number of infants reported as in documented care, in active followup, or lost to care were reported as follows:

	N	%
In Documented Care	215	76
In Active Followup	48	17
Lost to Care	21	7
	284	100%

For the twenty-one infants lost to care, the reported reasons for care closure were: moved out of county (7), moved out of state (6), parental withdrawal (1), can't locate (2), deceased (2), and other reasons (3).

Health Status

Two hundred and forty-four infants had information regarding their health status. Of this subgroup, the hundred thirty-six infants (56 percent) had reportedly "normal" health as reported by the primary care provider. One hundred-eight infants (44 percent) had one or more significant health concerns reported at this tracking period. These concerns are summarized in Table 14.

TABLE 14
HPIT: 3 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS (N = 108)
THURSTON COUNTY

Concern	Frequency
Central Nervous System	21
Pulmonary	16
Cardiac	13
Renal	6
Gastrointestinal	27
Growth Disorders	12
Malformation or Syndrome	19
Socio-Medical	20
Other	33

Developmental Status

Information regarding developmental status was available for two hundred and five infants at the three months tracking period. Of these infants, 190 (93%) were reported as "normal." Fifteen infants (7%) were noted to have developmental concerns.

Six Months

Receiving care. Two hundred seventy-seven six month tracking forms were available for review. At this tracking point the following infants were reported to be in documented care, follow-up or lost to care:

	N	%
In Documented Care	237	86
In Active Followup	22	8
Lost to Care	18	6
	277	100%

For the eighteen infants lost to care at the six month tracking period the reasons reported were: moved out of state/county (11), can't locate (3), parental withdrawal (1), and other reasons (3).

Health Status

Health Status information was available for two hundred and forty-nine infants. For this subgroup, one hundred fifty-five (62 percent) had reportedly "normal" health. Ninety-four (38 percent) had one or more significant health concerns reported at the six months tracking period. A summary of the reported health concerns appears in Table 15.

TABLE 15
HPIT: 6 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS
THURSTON COUNTY

Concern	Frequency
Central Nervous System	16
Pulmonary	7
Cardiac	8
Renal	3
Gastrointestinal	8
Growth Disorders	7
Malformation or Syndrome	16
Socio-Medical	7
Other	9

Developmental Status

Information regarding developmental status at six months was available for two hundred and five infants. Physician reporting indicated that ninety-one precent (186 infants) were developing "normally." Nine percent (19 infants) had developmental concerns noted at this tracking period.

Twelve Months

Receving care. Two hundred and thirty Thurston Conty infants had twelve month tracking forms available for review. The numbers of infants reported as in care, follow up or lost to care are as follows:

	N	%
In Documented Care	177	78
In Active Followup	31	13
Lost to Care	21	9
	229	100%

In the twenty-one cases lost to care the reported reasons were: moved out of state/county (14), can't locate (4), other reasons (3).

Health Status

Health status was reported for one hundred ninety-nine infants; thirty-one cases did not report health status at the twelve months tracking period.

Of the infants whose physicians reported health status data one hundred-eighteen (59 percent) had normal health. One or more significant health concerns were reported for eighty-one infants (41 percent). A summary of the health concerns is found in Table 16.

TABLE 16

HPIT: 12 MONTHS TRACKING FORM

SIGNIFICANT HEALTH CONCERNS (N = 26)

THURSTON COUNTY

Concern	Frequency
Central Nervous System	16
Pulmonary	15
Cardiac	11
Renal	4
Gastrointestinal	6
Growth Disorders	11
Malformation or Syndrome	14
Socio-Medical	13
Other	29

Developmental Status

Information regarding developmental status was available for one hundred sixty-five infants. In this group one hundred forty-two infants (86 percent) were reported as developing normally. Developmental concerns were noted for twenty-three infants (fourteen percent).

Eighteen Months

Receiving care. One hundred-forty infants had completed tracking forms at the eighteen months tracking point.

At this time point the numbers of infants reported to be in care, followup or lost to care are as follows:

	N	%
In Documented Care	97	69
In Active Followup	27	19
Lost to Care	16	12
	140	100%

For the sixteen cases lost to care the reported reasons were: moved out of state/county (11), can't locate (1) and other reasons (4).

Health Status

Health status information was available for one hundred twelve cases. At the eighteen month tracking period sixty-seven infants were reported as having normal health (sixty percent). Significant health concerns were noted in forty-four infants (forty percent). The significant health concerns are reported in Table 17.

TABLE 17
HPIT: 18 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS (N = 44)
THURSTON COUNTY

Concern	Frequency
Central Nervous System	14
Pulmonary	7
Cardiac	6
Renal	3
Gastrointestinal	3
Growth Disorders	4
Malformation or Syndrome	11
Socio-Medical	1
Other	12

Developmental Status

Information regarding developmental status was obtained for ninety-five cases at the eighteen months tracking period. Eighty infants (eighty-four percent) were reported as having normal development. Sixteen percent, or fifteen infants, were noted to have questionable or abnormal development.

Twenty-Four Months

Receiving Care. Fifty-nine infnats have reached the twenty-four months tracking period and have completed forms available for review. At this time point the numbers of infants in care, followup or last to care are as follows:

	N	%
In Documented Care	42	71
In Active Followup	11	19
Lost to Care	6	10
	59	100%

For the six infants lost to care the reported reasons were: moved out of state/county (2), can't locate (1), deceased (1), and other reasons (2).

Developmental Status

Information regarding developmental status was available for thirty-nine infants. Normal development was reported for thirty-one infants (seventy-nine percent). Twenty-one percent of all reported cases, or eight infants had questionable or abnormal development.

Health Status

Health Status Data was available for forty five infants. Normal health was reported for twenty-one infant (47 percent). Significant health concerns werenoted for twenty-four infants (53 percent). These concerns are reported in Table 18.

TABLE 18
HPIT: 24 MONTHS TRACKING FORM
SIGNIFICANT HEALTH CONCERNS (N = 24)
THURSTON COUNTY

Concern	Frequency
Central Nervous System	6
Pulmonary	4
Cardiac	2
Renal	1
Gastrointestinal	2
Growth Disorders	4
Malformation or Syndrome	7
Socio-Medical	3
Other	8

Thirty-Six Months

The first HPIT Project enrollees in Thurston County will reach the last tracking point in May and June, 1987. Information for this group will be reported at a later date.

Table 19 compares the reported rates of health and developmental concerns at each time point.

Table 19
HPIT Project
Comparison of Health and Developmental Status
in Thurston County

Tracking period	Health		Development	
	Normal	Abnormal*	Normal	Abnormal
3 Months	56%	44%	93%	7%
6 Months	62%	38%	91%	9%
12 Months	59%	41%	86%	14%
18 Months	60%	40%	84%	16%
24 Months	47%	53%	79%	21%

* Abnormal health is indicated by the reporting of one or more significant health concerns

THURSTON COUNTY: PILOT PROJECT CONTINUITY OF CARE

The pilot phase of the Thurston County HPIT Project has been successful in maintaining greater than seventy-six percent of the project enrollees in ongoing, documented well child care.

Active follow up at any one time point ranged from eight to nineteen percent. The local HPIT coordinator conducted followup activities including telephone calls, letters, and home visits to reconnect these infants with the health care system. The percentage of infants in Thurston County who require additional followup to maintain care appears to be approximately four percent higher than in Whatcom County. Table 20 illustrates the continuity of care in Thurston County.

TABLE 20
HPIT: THURSTON COUNTY
CONTINUITY OF CARE
1984-1987

Tracking Period	% In Care	% In Active Followup	% Lost to Care
3 months	76	17	7
6 months	86	8	6
12 months	78	13	9
18 months	69	19	12
24 months	71	19	10
Averages	76%	15%	9%

Reported Use of Community Services

Each tracking form sent to the primary care providers of high priority infants requests information regarding the types of community services utilized by high priority infants and their families. This information was obtained to evaluate the number and type of services used, and as a way to plan for services in the future.

plan for services in the future. All high priority infants enrolled in the tracking system are followed by the Thurston County Health Department.

Information regarding the use of community services was available for greater than eighty percent of all Thurston County HPIT Project enrollees. Table 21 reports the most frequently reported services and the numbers of infants using those services at each tracking point.

TABLE 21
HPIT: THURSTON COUNTY
MOST FREQUENTLY REPORTED COMMUNITY SERVICES
(Number of Cases)

Tracking Periods	Service Categories				
	N Reporting*	Crippled Childrens Services	WIC	Public Health Dept.	Referral Consultation
3 months	216	14	75	192	11
6 months	230	17	89	212	15
12 months	188	14	80	174	7
18 months	101	9	36	98	3
24 months	33	4	6	30	5
36 months	---	---	---	---	---

Key: WIC = Women, Infants and Children, Supplemental Food Programs
*Valid Cases reporting use of one or more community services. Some valid cases may use as many as five community services concurrently.

SECTION III

PILOT PROJECT FINDINGS

SUMMARY FINDINGS
PILOT PROJECT ENROLLEES

During the identification period for the Pilot Phase of the Washington State High Priority Infant Tracking Project (1982 to April 30, 1986), 766 eligible infants from the Whatcom and Thurston pilot sites have been identified. The identification forms for this group of high priority infants has been analyzed to provide a composite picture of high priority infants. As this group moves through the tracking phase additional data collection will continue. The present enrollees can begin to provide preliminary data regarding the outcome of high priority infants in the pilot phase of the project.

High Priority Infants: Characteristics at the Time of Identification

For the pooled group of identified infants (N=766), the trend toward a preponderance of males continued (58 percent male, 42% female). The mean birthweight for this group was 2873 grams (S.D. = 853 grams) and the mean gestational age was 37.5 weeks with twenty-four percent (N=168) of the cases reporting a gestation age of 40 weeks.

Maternal Age

Information regarding maternal age was attempted, but was reported for only two hundred fifty eight cases. Based on this limited data set, the range of maternal age was from thirteen to forty-six years, with a mean age of twenty-three years. In this subset of 258 mothers, forty-eight percent (N=123) were nineteen years of age or younger at the time of the high priority infant's birth.

Categories of Risk in the Pilot Project Enrollees

The identification criteria of the Washington State High Priority Infant Tracking Project attempt to incorporate the four major risk categories: established risk, biological risk, and environmental risk, as well as combinations of environmental with established or biological risk. The National Center for Clinical Infant Programs has provided a conceptual model

for categorizing risk criteria. Their definitions were adopted in our analysis. They are as follows:

Definitions

"Established Risk" conditions include, but are not limited to, the following kinds of disorders: Down Syndrome, hydrocephaly, Spina Bifida, Cerebral Palsy, orthopedic problems, medical concerns expected to impinge on developmental progression, congenital anomilies, and hearing and vision impairments.

"Biological Risk" involves infants and children presenting a history of prenatal, perinatal, neonatal, and early developmental events suggestive of biological insult(s) to the developing central nervous system, such as prematurity, abnormalities of tone, delay in achieving gross or fine motor milestones, abnormal neurological exams, unusual behaviors, feeding difficulties, etc.

"Environmental Risk" involves the potential for delayed development because of limiting early environmental experiences at family situations, such as parental age, parental stress, developmental disability of father or mother, maternal or paternal substance abuse or neglect, etc.[1]

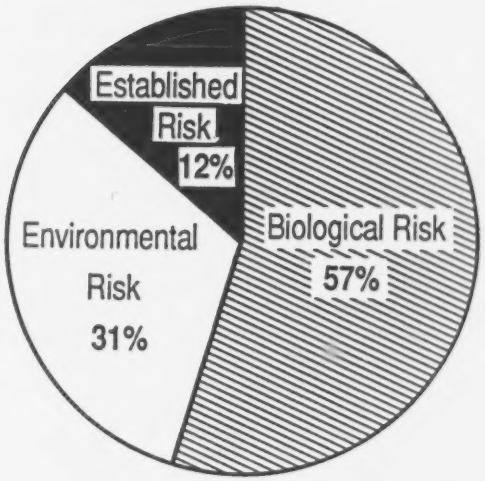
All identification forms were analyzed and categorized accordingly. The major risk categories were first reviewed. Cases were sorted by the PRIMARY concern noted on the identification form.

The categorization includes cases with multiple risk problems. The distribution of major categories was as follows:

Biological Risk: 52% of all indicators (N=391)
Environmental Risk: 31% of all indicators (N=244)
Established Risk: 12% of all indicators (N=145)

See Figure 9 for a representation of this data.

Figure 9
HPIT Project
Distribution of Risk Categories



Further segmentation of the categories was attempted to isolate the specific combinations of factors, as well as the actual number of cases with one risk category only. This information is reported in Table 22. The information reported is based on the total number of high priority indicators reported at the time of identification. Anyone enrolled may have more than one indicator of high priority.

TABLE 22
HPIT PILOT PROJECT: 1982-1986
RISK CATEGORIES (N = 758)

	% of All Indicators	N
Biological Risk Only	35	N=269
Environmental Risk Only	19	N=145
Established Risk Only	11	N=84
Biological + Established Risk	5	N=35
Biological + Environmental	10	N=73
Established + Environmental	2	N=12
Biological + Established + Environmental	2	N=14
Other	16	N=126

Notes: [A]The rates of identification for each category appear to be consistent when controlled for county and project year.

[B]Information regarding high priority criteria was not available for eight cases.

Indicators of High Priority

All high priority indicators were examined to determine the frequency of each indicator singly, and in combination with other high priority indicators. Multiple indicators were noted for sixty-six percent of the infants (N=515). Single indicators were noted in two hundred fifty infants, or thirty-three percent of the total number of enrollees.

See Table 23 for specific indicator data.

TABLE 23

HPIT PROJECT: 1982-1986

WHATCOM/THURSTON COUNTIES

FREQUENCY OF HIGH PRIORITY INDICATORS

High Priority Indicator	N (alone)	N combined	%IN combination	Most Frequent Other Factor
Birthweight≤2500 Grams (LBW)	33	249	88%	Prematurity (n=189) SGA (n-49) Soc/Env/Par (n=64) Other Prob (n=62) Respiratory (n=37) Maj Birth Def (n=19)
Birthweight Less than 10% (SGA) Small for Gestational Age	2	66	97%	LBW (n-49) Soc/Env/Par (n=28) Other Prob (n=21) Prematurity (n=15)
OFC Less than 10th Percentile or Greater than 90th Percentile	3	26	90%	Maj Birth Def (n=11) Other Prob (n=11) SGA (n=9) Env/Soc/Par (n=7)
Apgar<4 at 5 Minutes	1	9	90%	Low Birth Wt (n=5) Prematurity (n=4) Respiratory (n=5)
*Intracranial Hemorrhage (ICH)	0	17	100%	Prematurity (n=13) LBW (n=12) Seizures (n=7)
Seizures	7	16	70%	Respiratory (n=9) ICH (n=7) Other Problems (n=7)
Neurological Abnormality	1	21	95%	Respiratory (n=9) Other Problems (n=9) Maj Birth Def (n=9)
Acquired CNS Infection	1	4	80%	Other Problems (n=2)
Hyperbilirubinemia (≤ 20mg%)	22	17	44%	Other Problems (n=9) Respiratory (n=6) Prematurity (n=4)

Major Birth Defect	42	77	65%	Other Prob (n=35) Low Birth Wt (n=19) Prematurity (n=17) Respiratory (n=18) Parenting Rsk (n=20)
*Hearing/Vision	1	8	88%	Low Birth Wt (n=6) Prematurity (n=5) Maj Birth Def (n=3)
Congenital Infections	4	14	77%	Other Prob (n=11) Prematurity (n=5) SGA (n=5)
Mother Less than 15 Years	9	26	74%	Env/Soc/Par (n=24) Other Problems (n=8)
Environmental/Social/ Parenting	47	186	80%	Other Prob (n=96) Low Birth Wt (n=64) Prematurity (n=47) SGA (n=28) Maj Birth Def (n=20) Respiratory (n=22)
Prematurity	1	227	99%	Low Birth Wt (n=189) Other Prob (n=62) Env/Soc/Par (n=47) Maj Birth Def (n=17) SGA (n=15) ICH (n=13)
Respiratory	27	115	81%	Other Prob (n=63) Low Birth Wt (n=37) Prematurity (n=48) Maj Birth Def (n=18) Env/Soc/Par (n=22)

Note: Factors occurring less than three times in combination are not tabled. Each case may have one or more factors listed.

* Indicates a high priority indicator occurring only as a combined condition.

Predictive Ability of Identification Criteria

The ability to predict later health and/or developmental outcomes was examined for each identification criteria. A subgroup of 142 infants with completed health and development data for the 3, 6, 12 and 18 months tracking periods were used for this analysis.

A significant relationship between Major Birth Defects or Syndromes and later abnormal or questionable health status ($p \leq .001$) was demonstrated.

A trend toward a similar significant relationship was also noted for developmental concerns.

The relationship between early detection of birth defects and later outcomes will be further explored.

TABLE 24

MAJOR BIRTH DEFECTS OR SYNDROMES

INCIDENCE OF HEALTH AND DEVELOPMENTAL CONCERNS

(N = 30)

	Developmental Concerns		Health Concerns	
	Ratio	Relative Risk	Ratio	Relative Risk
3 months	7:30	3.5*[a]	18:30	2.7*[b]
6 months	7:30	2.3	16:30	2.7*[b]
12 months	9:30	2.0	18:30	2.1*[b]
18 months	8:30	2.7*[a]	20:30	2.5*[b]

*[a] $p \leq .05$

*[b] $p \leq .005$

Predictive Ability of Multiple Identification Criteria

The relationship between multiple identification criteria and later health and developmental outcomes was examined for the same subset of 142 infants. No evidence of a significant relationship between multiple high priority indicators and later outcome was noted.

Predictive Ability of Health Status

The relationship between early health status and later developmental outcome was examined. Relative Risk calculations and chi-square analysis were used to examine these data. A significant relationship is indicated between early abnormal health and later developmental concerns. This relationship appears to be stable and significant at each tracking point examined. See Table 25.

Table 25
HPIT Project
Predictive Ability of Health Concerns
Based on 142 cases with complete reporting

Abnormal Health Status	Prevalence of Developmental Problems			
	3 months	6 months	12 months	18 months
3 Months				
percentage	26%	31%	38%	29%
relative risk	8.7*	6.2*	3.8*	4.1*
6 Months				
percentage		45%	53%	40%
relative risk		45*	2.3*	10.3*
12 Months				
percentage			45%	31%
relative risk			13.6*	9.5*
18 Months				
percentage				31%
relative risk				9.5*

*Probability of corected Chi Square < .5

Longitudinal Analysis

The previously mentioned subset of 142 infants with completed data through the eighteen month tracking period were utilized for a longitudinal analysis of the sensitivity and specificity of each tracking period for the identification of health and/or developmental concerns. Ratings of sensitivity in these two correlations refer to the percentage of infants noted to have abnormal health at an earlier tracking period than continued to have health or developmental concerns at the eighteen month period. Specificity in this analysis refers to the percentage of infants who appear to have normal health at an earlier period and appear to have both normal health and/or developmental status at the later tracking point of eighteen months.

Health Status

Health status at three, six, twelve and eighteen months is represented in Table 26. Abnormal health status at the early tracking periods appear to be a reliable and significant indicator of later abnormal health at the eighteen month period.

Developmental Status

Developmental status was also examined. This data is contained in Table 27. The relationship between early abnormal health status and later developmental concerns appears to be significant at all tracking periods.

Table 26
HPIT Project
Sensitivity and Specificity of Health Problems
N=142

Health Status	Abnormal Health Status at 18 Months	
Abnormal Health at 3 Months	Sensitivity	51% *
	Specificity	82%
	False Positives	38%
	False Negatives	25%
Abnormal Health at 6 Months	Sensitivity	55% *
	Specificity	89%
	False Positives	26%
	False Negatives	22%
Abnormal Health at 12 Months	Sensitivity	71% *
	Specificity	84%
	False Positives	29%
	False Negatives	16%

* Probability of Corrected Chi Square ≤ .001

Note: Abnormal health is indicated by reporting of one or more significant health concerns

Table 27
HPIT Project
Sensitivity and Specificity of Developmental Problems
N=142

Developmental Status	Developmental Status at 18 Months	
Abnormal Development at 3 Months	Sensitivity	37% *
	Specificity	94%
	False Positives	50%
	False Negatives	9%
Abnormal Development at 6 Months	Sensitivity	53% *
	Specificity	93%
	False Positives	44%
	False Negatives	7%
Abnormal Development at 12 Months	Sensitivity	89% *
	Specificity	93%
	False Positives	35%
	False Negatives	2%

* Probability of Corrected Chi Square ≤ .001

Abnormal Development as indicated by report of primary care provider

Summary Findings: Health and Developmental Outcomes of High Priority Infants

Pooled data from both Whatcom and Thurston Counties indicated that previously reported rates of health and developmental concerns have remained stable. At each tracking period from three to thirty-six months approximately forty percent of the high priority infants had ongoing health concerns. The reported percentage of developmental concerns ranged from ten percent at the three month tracking period to thirty-one percent at the thirty-six month tracking period, with the reported percentage rising at each tracking period. The overall rate of developmental concern is eighteen percent.

References

1. National Project O-3 Survey Report. "Identifying and Serving High Risk Infants: Results of an Informal Survey of Project Zero to Three States," National Center for Clinical Infant Programs, Fall, 1985.

SECTION IV

HIGH PRIORITY INFANTS WITH ENVIRONMENTAL, SOCIAL OR PARENTING (ESP) INDICATORS

The following section addresses the HPIT Project Enrollees identified as representing infants with environmental, social or parenting concerns (ESP).

Michelle A. Bell, Ph.D. has contributed the following section to this report. Her extensive efforts in the compilation and interpretation of this data are greatly appreciated by the project staff.

Infants with environmental, social or parenting indicators comprise a special sub-set of high priority infants. Of the 766 infants identified for HPIT, 232 (31%) had environmental, social or parenting (ESP) indicators, either alone or in combination with medical or biological indicators. Separate analyses were done to determine continuity of care, use of community services, and health and developmental problems of the infants with ESP indicators as compared to infants with medical or biological indicators only. This section reports the results of those analyses.

One hundred fourteen (114) of the infants with ESP indicators were from Whatcom County, representing 26% of high priority infants identified for that county. The remaining 118 were from Thurston County, representing 36% of infants identified for that county. The difference between the counties in the proportion of infants with environmental, social or parenting risk factors was statistically significant (chi square = 7.84, $p \leq .01$). This difference between the counties may indicate a difference in the demographic characteristics of the two areas, or differences in the procedures by which high priority infants were identified, or both. Infants with environmental, social or parenting indicators from both counties were combined for the remaining analyses.

Description of Infants with ESP Indicators

The majority (185/232) of the infants identified by ESP indicators also had one or more medical or biological indicators. For this "doubly vulnerable" group, the other indicators identified most frequently were: other minor problems combined (n=76), low birth weight (n=64), prematurity (n=47), birth weight _ 10th percentile for gestational age (n=28), respiratory problems (n=22), and major birth defect or syndrome (n=20). This group will be referred to as "ESP +." The remaining 47 infants with ESP indicators had no medical or biological risk. They will be referred to as "ESP only."

The ESP indicators are shown in Table 28, by frequency of their occurrence. The first indicator, mother $\leq$ 15, was specified on the identification form. Remaining indicators were derived through content analysis of an open-ended question in which health personnel were asked to identify "significant environmental, social and parenting risk." The list of

indicators and their frequencies was left specific, with the expectation that some categories could be collapsed at a later time.

TABLE 28
HPIT PILOT PROJECT
ESP INDICATORS, BY FREQUENCY OF OCCURRENCE

Indicator	ESP only	ESP +	Total
Mother ≤ 15			24
Mother 16-20 and single	22	28	50
Mother 20 and single	11	8	19
Mother single, age not specified	4	9	13
Young parents (marital not spec.)	13	36	49
Delayed/little/no prenatal care	30	14	34
Maternal ment. ill. past or current	9	3	12
Mother developmentally disabled	6	4	10
Maternal substance abuse	9	8	17
Maternal medical or physical prob.	4	8	12
Maternal history of begin sex. ab.	1	1	2
History of/current CPS involvement	12	3	15
History of/current domestic violence	3	2	5
Financial problems/unemployment	2	9	11
Unstable or poor living arrangements	4	6	10
Questionable bonding/responsibility	2	4	6
Inexperience/questionable infant care	5	6	11
Family conflict/dysfunction/separ.	6	11	17
Other children 5 years old in home	7	6	13
Home birth	-	2	2
ESP not described	1	25	26

Clearly, many indicators occurred in combination with one another. The most frequent combinations were young and/or single parents, with one or more

other children in the home, and either unstable living conditions or financial problems. The data also indicated that ESP indicators took on special importance to health personnel when the infant had other medical or biological problems. The comments indicate a concern that the ESP risks would make it difficult for parents to provide the extra care and attention required for infants with medical or biological problems.

Continuity of Care

Eighty-three percent (193/232) of the infants identified with ESP indicators were enrolled in the tracking project. By comparison, 77 percent (403/525) of infants with only medical or biological indicators were enrolled. The difference in enrollment between the two groups was not statistically significant, indicating that the ESP infants were equally likely to be enrolled as were the non-ESP infants.

Once enrolled, however, infants with ESP risk were significantly less likely to receive consistent ongoing health care than were those only medical or biological risk, as indicated by the project tracking forms for 3, 6, 12, and 24 months. Table 29 illustrates the differences between the groups in continuity of care, as determined by chi square analysis. DAta reported previously indicated a significant difference between the two groups only for the 6 month tracking period. The variability between the two reports indicates the need for further analysis of continuity of care as more data become available.

TABLE 29
HPIT PILOT PROJECT
INFANTS IN CARE AT TRACKING PERIODS

Tracking Period	ESP Risk		Med/Bio Risk Only		
	N in Care	% in Care	N in Care	% in Care	p
3 months	141/178	79	320/369	87	.05
6 months	136/166	81	330/365	90	.01
12 months	109/148	73	259/292	88	.001
18 months	65/90	72	179/221	81	n.s.
24 months	38/58	66	115/132	87	.001

Continuity of care was further analyzed for infants with ESP indicators only and those with ESP indicators in combination with medical or biological indicators. The purpose of this analysis was to determine whether the presence of medical or biological risks made a difference in continuity of care. The ESP only group had a lower proportion of infants in care at the 3, 6, 12, and 24 month tracking periods that did the ESP plus medical/biological group. However, none of the differences were statistically significant. The presence of medical or biological risk factors made no difference in continuity of care for infants with ESP risk.

Examination of the reasons given by primary care providers for infants not receiving care at each tracking period revealed that "don't know/can't locate" was cited 2.5 times more frequently for both groups of infants with ESP risk than for those with medical or biological risk only. This difference was significant ($p \leq .02$).

Use of Community Services by Infants with Environmental, Social or Parenting Risk

Community service use was recorded for 75% or more of the HPIT cases for all tracking periods except 24 months. The data were analyzed to determine whether infants with ESP risk differed from those without ESP risk in the extent to which they used community services, and in the types of services they used. The results, reported in Table 30, indicate that significantly more infants with ESP risk than with medical or biological risk only used community services as reported at the 3, 6 and 12 month tracking periods. These results must be viewed in light ot the fact that only 75% of tracking forms contained information on use of community services.

TABLE 30
HPIT PILOT PROJECT
PERCENT OF INFANTS USING COMMUNITY SERVICES

	ESP Risk		Med/Bio Risk Only		
	N	%	N	%	p
3 months	110/142	78	177/305	58	.0001
6 months	116/142	82	194/302	64	.0003
12 months	85/109	78	154/242	64	.0110
18 months	37/59	63	107/174	62	n.s.
24 months	15/33	46	45/87	52	n.s.

The infants and families used a variety of services that included: public health nursing, referral-consultation, children's protective services (CPS), Supplemental Food Program for Women, Infants and Children (WIC), Crippled Children's Services (CCS), mental health and special education for parents, physical and respiratory therapies, and apnea monitoring, among others. Public health nursing service was the most frequently used service: 75 to 80% of infants who used community service at each tracking period used this service. Public health nursing was used equally by those with ESP risk and with medical or biological risk only. WIC was used by 30 to 37% of all infants; as would be expected, WIC was used by more infants with ESP risk indicators than by those without. CPS was also used by more infants with ESP risk indicators, while CCS and referral-consultation services were used by more infants with only medical or biological risk factors.

Predictive Ability of Environmental, Social and Parenting Risk for Health and Development of Infants

Two hundred forty-two (242) infants had completed tracking forms for the 3, 6, and 12 month periods which included information on health and development status. Sixty-eight (28%) of those with completed forms were identified as having ESP indicators; 174 (72%) had medical or biological

indicators only. The health and developmental status of the two groups at each tracking period is shown in Table 31.

TABLE 31
HPIT PILOT PROJECT
INCIDENCE OF HEALTH AND DEVELOPMENTAL PROBLEMS
BY TYPE OF RISK FACTORS (N = 242)

	Proportion with Developmental Problems			Proportion with Health Problems		
	3 mo.	6 mo.	12 mo.	3 mo.	6 mo.	12 mo.
ESP Risk	4%	10%	18%	29%	32%	31%
Ratio	3:68	7:68	12:68	20:68	22:68	11:68
Rel. Risk	*	.9	.9	.8	.9	.8
Med/Bio	10%	11%	17%	37%	37%	37%
Ratio	18:174	20:174	29:174	64:174	64:174	64:174
Rel. Risk	*	1.1	1.1	1.3	1.1	1.2

* Relative risk was not calculated for cells with fewer than 5 cases, to reduce statistical error.

Table 31 indicates two important points. First, infants with medical or biological risk factors only were slightly more likely to have both health and developmental problems at all three tracking periods than were those with environmental risk factors. Second, more infants in both groups were assessed as having developmental problems at each successive tracking period. Unfortunately there were not sufficient numbers of cases with complete health and development ratings at the 18 and 24 month tracking periods to analyze whether this trend continued beyond 12 months. That analysis will have to wait until more data become available.

In summary, the majority (80%) of infants identified for HPIT as having ESP risk also have other medical or biological risk indicators. Infants with ESP risk were as likely to be enrolled in HPIT as those with biological or

medical risk only. However, they were significantly less likely to receive consistent, ongoing health care at the 3, 6, 12 and 24 month tracking periods. There was no difference in this finding for infants with ESP risk only and those with ESP plus medical or biological risk.

Infants with ESP risk who remained under the care of the primary physician made appropriate use of community services at all tracking periods.

Finally, infants with ESP risk consistently experienced fewer health and developmental problems through the first 12 months of life. However, all of these results are interim and must be reviewed as more data become available.

SECTION V

DISCUSSION

Discussion

The Washington State High Priority Infant Tracking Project has successfully completed four years of pilot study. During this period, 766 eligible infants were identified. Information obtained from the coordinated, comprehensive followup of these infants has contributed to program revisions and modifications that are necessary before expansion of the project can begin.

The success of the pilot project can be effectively evaluated in terms of the major program objectives.

Objective #1

To help parents keep their child under the care of a primary care physician.

For both counties, the percentage of infants lost to ongoing healthcare for any reason ranges from five to sixteen percent. At any one tracking point an average of eight percent of the cases are lost to further tracking.

An average of eighty-two percent of the cases are in ongoing healthcare at any given tracking point. The remainder of the cases are comprised of infants who are in some phase of active followup to return them to the health care system. As previously mentioned, this followup is coordinated at the local level by a community health nurse. The percentage of infants requiring intensive followup to return to the healthcare system ranges from two to seventeen percent. An average of eleven percent was obtained for all tracking periods.

When compared to pre-pilot data, which indicated less than fifty percent combination in ongoing documented care, the percentage of infants in known care - or in active followup has increased dramatically.

Objective #2

To promote early identification of infants requiring further evaluation or services.

Information regarding the use of services was most readily available for Thurston County HPIT Project enrollees. In Thurston County, approximately

seventy-five percent of all enrollees have used a public health department service at one or more tracking periods. The range of service varied from well child clinic to immunization clinics, visits to the health mobile, breast feeding support, etc. In addition, one-third of the Thurston infants were using the services of the Women, Infants, and Children Program (WIC) at one or more tracking periods.

At the time of the last tracking period, thirty-six months' information regarding services available for preschool developmentally delayed children, as well as information regarding local school district Child Find activities are mailed to both parents and providers. This system facilitates connection with available school services at the termination of tracking.

We hypothesize that the ongoing contact with the public health department will continue to facilitate referral to appropriate services for high priority infants and their families. This linkage will be further explored.

Objective #3

To assist in planning for the health and educational needs of the children of Washington State.

Data collected from the HPIT Project Pilot phase has been shared with state agencies, programs, and individuals charged with the responsibility for future planning. This objective is especially critical to assist in planning for the implementation of P.L. 99-457 in Washington State. Specifically, project data is shared on an ongoing basis with the Birth Defects Monitoring Program, local health districts, Birth-to-Six State Planning Project, local school districts, and health care providers, through publications and a quarterly newsletter. Multiple agencies within Washington that are concerned with children's issues receive ongoing, updated information.

During the pilot phase, the Washington State High Priority Infant Tracking Project has demonstrated that high priority infants can be identified and maintained in a collaborative system of ongoing healthcare.

Expansion of the project appears appropriate at this time due to federal, state, and local interest and concern.

Appendix A

HIGH PRIORITY INFANT IDENTIFICATION FORM OF WASHINGTON STATE CASE NUMBER _____

PATIENT DATA

CHILD'S NAME: _____
(last) (first) (middle)

DATE OF BIRTH: _____ GESTATION (weeks): _____ ( ) Male ( ) Female

Infant born in this hospital: ( ) Yes ( ) No. If no, hospital of birth: _____

MOTHER'S NAME: _____
(last) (first) (middle)

FATHER'S NAME: _____
(last) (first) (middle)

GUARDIAN, if any: _____
(last) (first) (relationship)

ADDRESS: _____ TELEPHONE: _____
(street or route no.) (town)

_____
(county) (zip)

Name of persons other than parents who will know where child can be located:

1. _____
(name) (address) (telephone no.)

2. _____
(name) (address) (telephone no.)

HIGH PRIORITY INDICATORS (CHECK ALL THAT APPLY)

( ) Birth weight ≤5 lbs. 8 oz. (≤2500 gms.) BIRTH WEIGHT: _____ gms.
( ) Birth weight ≤10th %tile for gestational age (SGA) _____ lb. _____ oz.
( ) Head Circumference (OFC) ≤10th %tile or ≥90th %tile for gestational age OFC. _____ in./cms.
( ) Apgar score less than 4 at 5 minutes APGAR _____
( ) Intracranial hemorrhage
( ) Seizures
( ) Clinical impression of neurological abnormality DESCRIBE: _____
( ) Acquired CNS infection (e.g., meningitis) DESCRIBE: _____
( ) Hyperbilirubinemia (≥20 mg%) mg%: _____
( ) Suspected/confirmed hearing impairment
( ) Suspected/confirmed visual impairment
( ) Major birth defect or syndrome DESCRIBE: _____
( ) Congenital fetal infection: ( ) toxoplasmosis ( ) rubella ( ) herpes ( ) cytomegalic virus ( ) syphilis
( ) Confirmed congenital hypothyroidism
( ) Confirmed PKU
( ) Mother 15 years of age or under AGE _____ yrs.
( ) Significant environmental, social, or parenting risk DESCRIBE: _____
( ) Other problems: _____

FORM COMPLETED BY: _____ DATE: _____

I have reviewed the above information and believe it to be correct.

_____ DATE: _____
(Attending Physician Signature)

PARENT'S PERMISSION

I have had the "High Priority Infant Tracking Program" explained to me orally and in writing and agree to having my baby enrolled. I understand that enrolling my infant in this program requires sending certain personal and medical information as indicated above to my child's health care provider and to the local health department where my child resides presently or in the future. I understand I can withdraw my child from this program at any time. My child's health provider is:

_____
(name of health provider)

_____
(address) (town) (state) (zip)

_____
(Witness' Signature) (Parent's Signature)

_____
(Date) (Date)

( ) Refused tracking system: _____

TIME RECORD FOR THIS PATIENT

HOSPITAL STAFF
TIME SPENT ON HPIT: Please check appropriate time spent in each activity.

IDENTIFICATION (eg. identifying infant; preparing forms and charts, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

PARENT CONTACT (eg. obtaining consent; explaining program, etc.)
( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

HEALTH DISCIPLINE CONTACTS (eg. communication with other staff relative to HPIT activities)
( ) None ( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min.
( ) 30-35 min. ( ) Other specify in minutes: _____

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Appendix B

FORM SENT TO: _____ CASE NUMBER _____

HIGH PRIORITY INFANT TRACKING FORM OF WASHINGTON STATE

PATIENT DATA

CHILD'S NAME: _____ DATE OF BIRTH: _____

PARENT'S NAME: _____ TELEPHONE: _____

ADDRESS: _____

(street or route number) (town) (county) (zip)

If different from above, please correct: _____

RETURN FORM TO

AGENCY: _____ ATTENTION: _____
(person requesting information)

ADDRESS: _____ TELEPHONE: _____

Check TRACKING CONTACT:( )3-4 mos.( )6-7 mos.( )12 mos.( )18 mos.( )24 mos.( )30 mos.( )36 mos.

TRACKING DATA

Is this child still receiving health care from you? ( ) Yes ( ) No

If no, indicate reason: ( ) Don't know ( ) Cannot locate ( ) Deceased

( ) Moved to: _____ (state or county)

( ) Referred to another physician: _____

Address: _____

( ) Other: _____

Please indicate:

I. HEALTH STATUS: ( ) Normal ( ) Other. If other, check MAJOR problems and specify as necessary below.

( ) A. CNS. ( ) Cerebral Palsy ( ) Seizures ( ) Hydrocephalus

( ) Structural defects, specify: _____

( ) Other: _____

( ) B. Pulmonary, specify: _____

( ) C. Cardiac, specify: _____

( ) D. Renal, specify: _____

( ) E. GI, specify: _____

( ) F. Growth Disorders: ( ) Failure to thrive

( ) Head Circumference (≤3rd %tile or ≥97th %tile)

( ) G. Malformation or syndromes, specify: _____

( ) H. Sociomedical: ( ) Child abuse/neglect ( ) Other, specify: _____

( ) I. Other, specify: _____

II. BEHAVORIAL/SENSORY DEVELOPMENT

A. Developmental Milestones — considering age (corrected for prematurity if any)

1. Personal-social:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
2. Fine motor:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
3. Gross motor:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
4. Language:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment
5. Mental:	( ) Normal	( ) Questionable	( ) Abnormal	( ) in treatment

B. Vision: ( ) Normal ( ) Abnormal, specify: _____

C. Hearing: ( ) Normal ( ) Abnormal, specify: _____

D. Other, specify: _____

III. INTERVENTION SERVICES

A. With respect to the problems mentioned above, has the child and family received services from other community agencies during the past year?

( ) No ( ) Yes. If yes, specify type: _____

B. If no, why is the child not receiving these services? ( ) managing problems myself

( ) family refused ( ) appropriate services not available in community

Date last seen by you _____.

TIME RECORD

FOR PRIMARY HEALTH CARE PROVIDER ONLY: Please check appropriate box indicating time spent in completing form.

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____

CASE CLOSURE

FOR PHN ONLY:

Date of closure: _____ Reason: Moved out of ( ) state or ( ) county

( ) Parental permission withdrawn

( ) Cannot locate ( ) Deceased

TIME RECORD FOR THIS PATIENT

Time spent on HPIT: Please check appropriate time spent in activity

ADMINISTRATION (eg. developing file; sending tracking form, etc.)

( ) 1-5 min. ( ) 6-11 min. ( ) 12-17 min. ( ) 18-23 min. ( ) 24-29 min. ( ) 30-35 min.

( ) Other, please specify in minutes _____.

PARENT CONTACT (eg. activities related to tracking lost infant; follow-up, etc.)

( ) none ( ) 1-20 min. ( ) 31-60 min. ( ) 61-120 min. ( ) 2-3 hrs. ( ) 3-4 hrs.

( ) Other, please specify in hours _____

PRIMARY HEALTH CARE PROVIDER CONTACT (eg. communication relative to HPIT activities)

( ) none ( ) 1-10 min. ( ) 11-20 min. ( ) 21-31 min. ( ) 32-42 min. ( ) 43-53 min.

( ) 54-64 min. ( ) Other, please specify in hrs. _____

COPY TO: WHITE — HEALTH DEPARTMENT CANARY — HPIT PROJECT

DSHS 13 849 (3/83) QS A V6

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